Evaluation of the Advance Care Planning Programme

Prepared for Health Quality and Safety Commission

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# Authors

Sally Duckworth and Anna Thompson
Main messages and actions

This report for the Health Quality and Safety Commission presents the findings of the evaluation of the Advance Care Planning (ACP) Programme. The purpose of this evaluation is to inform the five-year strategic plan for ACP.

Consumer and whānau experience of ACP is positive

- ACP is relevant to consumers nearing the end of their life. Most consumers found having conversations to develop their plans beneficial and restorative. Consumers felt having a plan minimised the burden on whānau for making decisions, and avoided conflict in end of life decisions.
- Consumers valued developing their plans with someone they could form a relationship with over time or with someone they had a relationship with. This is particularly important for Māori and Pacific consumers. Consumers felt empowered having in-depth conversations about end of life planning in their homes.
- Consumers need help with writing and loading plans. This makes completion more convenient, reliable and timely.
- Consumers want all health providers across New Zealand to be able to access their plans. They want to ensure that health providers will follow their end of life wishes if they cannot speak for themselves.
- Some consumers and whānau had used plans to discuss and negotiate end of life treatment and care. These consumers and whānau were Pākehā and had high health literacy, suggesting that in spite of having plans people need health literacy to negotiate end of life health services.
- Health providers and consumers do not routinely review and update plans. Consumers felt plans should be updated annually or more frequently, when health deteriorates rapidly.

Everyone has a role in ACP

- Palliative care, oncology, renal and respiratory services are leading in developing advance care plans with consumers. These are good settings for developing and using plans.
- Acute settings are a good place to start ACP conversations but are not suitable for holding in-depth conversations. Few plans are being developed in these settings.
- Age-related residential care is also an ideal setting for developing plans. However, this sector has been slow to implement ACP.
- Primary care sits across the ACP pathway. However, uptake has been challenging, due to competing demands and time it takes to develop a plan.
- Coordinators are key to successfully implementing ACP and should continue until the programme becomes business as usual.
- The community has a role in implementing ACP (for example, starting conversations and developing plans). The community’s role is untapped.
ACP training is effective

- The programme has trained approximately 1,500 health providers to have conversations with consumers about ACP.
- Health providers participating in the training enjoyed it, and thought it was a valuable experience. However, some health providers and employers consider the Level 2 (two-day) training costly and long.
- Training improves providers’ confidence and skills to have conversations with consumers about ACP.
- Providers report applying learnings to practice. Consumers felt trained health providers listened and were knowledgeable, empathetic and professional when they developed their plans.
- Training is contributing to consumers achieving their future and end of life goals.
- ACP training is filling a gap in advanced communications training for the health workforce. There is an opportunity to redesign Level 1A and/or Level 2 courses to meet the workforce’s need for advanced communications training.
- The National ACP Forum needs refreshing so that it delivers value for money.

Resources could be improved

- The programme has a wide range of resources. These were developed with consumer, whānau and provider input.
- Resources are mainly in English. Pacific consumers need resources in their own languages.
- Some providers mentioned the resources were too long and not user friendly when having conversations with consumers.
- Resources are not visible to consumers in general practice waiting rooms and other health and community settings.
- An ACP coordinator or nurse mainly led consumers interviewed through the ACP process. Consumers therefore did not have to depend on resources to complete a plan.

Plans need to be accessible and easy to share

- The current system of storing and locating plans is resource intensive.
- The extent to which plans are accessible and shared varies across and within District Health Boards (DHBs).
- In most cases, paramedics and ambulance staff are not able to view patients’ electronic health records and therefore may not know that a consumer has a plan.
- There are strong benefits to being able to view plans as part of patient’s electronic health records.

Taking the programme to the community

- Community meetings are effective at raising consumer awareness and demand for ACP.
- Some DHBs have undertaken a large number of meetings in aged residential care facilities and hospices, and other targeted community groups. However, DHBs have engaged less with Māori and Pacific communities.
- There is low awareness of Conversations that Count Day and the return on investment is likely to be low. However, there may be value in a consumer and community led public awareness campaign.

**Developing sustainable governance and leadership**

- The National Advance Care Planning Cooperative (the cooperative) has been invaluable for driving ACP in the early years.
- Leaders are championing ACP at regional, specialisation and consumer levels.
- The programme needs a permanent home and reliable funding for long-term sustainability.

**Monitoring, evaluation and research for the future**

- The programme needs a monitoring system to track progress and identify improvements.
- The strategic plan needs to be evaluated after five years.
- The programme needs to invest in research to create an evidence base for ACP in New Zealand.

**Our evaluation approach**

We based our findings on 65 stakeholder and consumer interviews, a survey of 483 people who received ACP training, administrative data, and a desktop review of international literature. The evaluation was conducted between December 2016 and March 2017.
Consumer and whānau experience of ACP is positive

An ACP Coordinator, hospice worker, oncologist, renal nurse, lawyer or a family member working in the health system, introduced most consumers to ACP. Consumers were interested in developing a plan once they were told about it. However, some Pacific consumers could not recall having conversations around end of life planning or developing their plans. This suggests that conversations and resources were not culturally appropriate for these consumers.

ACP is relevant for consumers and whānau

The programme is relevant to consumers nearing the end of their life. Plans are relevant for consumers following a terminal diagnosis or change in living situation, such as home downsizing or moving to age-related residential care. Plans are also relevant for consumers who are aging or have deteriorating health.

Most consumers found having conversations to develop their plans beneficial and restorative. They valued having conversations about what is important for them for future and end of life treatment and care. Some consumers used their plan to make other promises and requests. For example, one young man used his plan to make a bucket list of things he wanted to do before he died, and one older man used his plan to discuss his funeral wishes.

Consumers felt having a plan minimised the burden on whānau for making decisions. They also felt that plans minimised conflict within whānau who had different views on end of life treatment and care.

The programme is also relevant to consumers’ whānau. Plans help whānau support their whānau member’s end of life wishes and act on them if they can no longer speak for themselves. Whānau found this reassuring, and it helped with closure once the person died.

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1 An ACP Coordinator identified all consumers we spoke to for the evaluation. Most of these consumers had received considerable support completing a plan. Only one consumer had completed a plan without help. This is likely to have positively influenced their experience of ACP.

2 Singer et al. (1998) identified the following needs for consumers. For consumers, ACP is about preparing for death not just for medical incapacitation. While it increases autonomy and patient control, it is embedded in relationships and includes relieving burdens from others. ACP does not occur solely within clinician-patient context, relationships with family and loved ones are important. Additionally, the focus of ACP is the social process, as well as completing the forms.
Relationships are essential to having effective ACP conversations

Consumers valued developing their plans with someone they could form a relationship with over time or with someone they had a relationship with. This was especially important for Māori and Pacific consumers. Pacific consumers also preferred having conversations in their own languages.

Māori consumers and whānau felt it was important for the person developing the plan to understand Māori views around death and dying. They wanted key cultural practices around death and dying acknowledged and respected, for example the role of tikanga, waiata, karakia, maintaining mana, and strengthening and balancing relationships. For whānau, being with a dying whānau member may be a spiritual experience.3

Consumers felt it was important that the person who developed their plans understood their conditions and could answer basic health and legal questions. They did not think the person who developed their plans needed to be a highly trained health provider.

Consumers value conversations in their homes

In most cases, consumers developed plans in their own homes.4 Consumers felt empowered having in-depth conversations about end of life planning in their homes. They found it more convenient, relaxed, culturally appropriate and less hierarchical than if they had developed their plans in a hospital or general practice surgery.

Consumers need help writing and loading plans

Consumers liked their ACP Coordinator, oncologist or nurse helping them to write their plans. This made the process of drafting their plans easier and timelier. A few consumers had tried previously to write their future and end of life care wishes down, and found it difficult to articulate what they wanted. Some older and low-income consumers also did not have computers, or would have found it a burden typing and uploading plans.

Reviewing draft plans and sharing with whānau are important steps in the process

In most cases, consumers recalled reviewing their plans before signing. Consumers felt that this action made them feel like ACP is a partnership. Consumers felt that the person who developed their plans had captured their wishes. However, some consumers and whānau

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3 This approach is supported by research on palliative care for Māori (see Ministry of Health, 2014; Moeke-Maxwell, Nikora, & Te Awekotuku, 2010).
4 Research does not state one setting where ACP should occur. However, there is agreement that conversations take time and should be conducted with someone the consumer has a relationship with or has the capacity to build a relationship with.
found reviewing the plans upsetting as their conversations were ‘in black and white’ and their wishes were finalised.

Most consumers shared their plans with whānau so everyone understood their wishes. In some cases, plans made whānau more aware of consumers’ conditions. This positively changed how whānau related to consumers, for example, visiting consumers more, or sharing consumers’ care and support needs. This was particularly evident for Māori and Pacific consumers we interviewed.

Some consumers stored their plans with important documents for example, their will and power of attorney. Other consumers kept their plans in an accessible place for whānau, paramedic or ambulance staff.

**Consumers expect their plans to be accessible and shared across the health sector**

Consumers want all health providers across New Zealand to be able to access their plans. They want to ensure that health providers will follow their end of life wishes if they cannot speak for themselves. Most consumers wrongly believe their plan is visible to all health providers across New Zealand.

Consumers and whānau are often responsible for making plans accessible by sharing them with paramedics, ambulance, and hospital staff. This action places burden on consumers and requires a degree of health literacy, comprehension and whānau support.

Most consumers keep a hard copy of their plan in a visible place, such as in the fridge, kitchen cupboard, or hanging by the door. Consumers often carry a hard copy of their plan with them, if they go to hospital.

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### Nancy’s story

Nancy’s story is a good example of how a consumer’s experience met her expectation for sharing plans. Nancy is in her late 80’s and developed her plan a few years ago. The ACP Coordinator loaded it on the electronic system as a shared file when the plan was finalised. Her plan included not wanting cardiopulmonary resuscitation if she was in cardiac arrest.

In 2016, Nancy went to hospital for surgery. In the ward, the ACP Coordinator visited and reassured her that the surgical team had read her plan. The surgeon met her before surgery and said ‘we have read your plan and know your wishes should something happen in theatre’. This gave Nancy confidence and reassurance going into theatre that she would not receive cardiopulmonary resuscitation if she was in cardiac arrest.
Some consumers and whānau had used plans to discuss and negotiate end of life treatment and care

These consumers and whānau were Pākehā and had high health literacy, suggesting that in spite of having plans people need health literacy to negotiate end of life health services.  

Three consumers’ whānau had referred to plans nearing the end of life. In one case, a consumer’s partner used the plan to negotiate more home support to allow him to die at home. Whānau said plans had provided them with clear instructions to follow when consumers were unable to talk for themselves. Whānau felt confident making decisions knowing they were respecting their whānau members’ wishes.

Plans are not routinely reviewed to ensure consumers’ wishes are up to date

In most cases, consumers developed plans during their final years of life. However, in some cases consumers had developed their plans three or four years ago. In most of these cases, plans had not been updated to reflect their current situation and wishes. Consumers felt plans should be updated annually or more frequently, when health deteriorates rapidly.

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5 We interviewed 24 consumers and whānau for the evaluation. Of these, five identified as Māori and four had different Pacific backgrounds. Some of these consumers were less aware of their plans and how to use their plans to advocate for end of life care. Clinical experts interviewed identified concerns with inequitable access to and use of ACP among low-income, Māori, and Pacific communities.

6 Health providers we interviewed in general practices did have an automatic review process for plans. However, these were higher performing practices. Not all consumers we spoke to had had their plan reviewed.
Everybody has a role in ACP

Palliative care, oncology, renal and respiratory services are good settings for developing plans, and are leaders in ACP

Palliative care is championing ACP and is implementing it well. Historically, this service in both hospital and hospice settings has strong ties to ACP. Health providers often have ongoing relationships with consumers and visit consumers in their homes. These factors make it easier for staff and consumers to have conversations, develop, and use plans.

Oncology, renal, respiratory specialties are also championing ACP. These services also have long-term relationships with consumers. Nurses from these services also visit consumers in their homes. Staff can therefore more easily have conversations and prepare plans with consumers. Staff can use plans to inform care and adjust plans as consumers’ needs change.

Acute settings are a good place to start ACP conversations but are not suitable for holding in-depth conversations

Acute and emergency settings are a good place to check whether consumers have a plan and start conversations. This setting is also the right place to interpret and act on plans.

Some health providers routinely ask consumers whether they have a plan and refer them to their general practice or ACP Coordinator, if needed. However, other health providers do not initiate these conversations. Staff we spoke with had treated very few consumers with plans. It is therefore too soon to tell whether staff are interpreting and acting on plans in line with consumers’ wishes.

Acute and emergency settings tend to be unsuitable for developing plans. This is because there is limited opportunity for in-depth or a series of conversations.

Age-related residential care is also an ideal setting for developing plans, but has been slow to implement ACP

With some exceptions, the age-related care sector has been slow to implement ACP.

However, this setting is a good place for having ACP conversations and helping consumers to develop plans. Staff have day-to-day relationships with consumers and can update plans as

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7 Other specialised services also have long-term relationships with consumers and therefore could do ACPs. However, these were the main areas literature and stakeholders referred to.

8 Exceptions include Presbyterian Support Southland who had a strong push on ACP training for all staff in age-related residential care facilities.
consumers’ needs change. Consumers are often more ‘ready’ to have conversations, if they have moved from their own home, or entered a higher stage of care. However, it is important that consumers are cognitively competent when they have conversations and complete their plans. Given consumers’ time of life, health providers need to manage these conversations sensitively.

Primary care sits across the ACP pathway; uptake has been challenging

General practice is well placed to initiate and have conversations with consumers, develop plans, and act on and interpret plans.

While most general practices in Canterbury DHB are implementing ACPs, uptake in other DHBs has been low.

Key challenges for general practices to implement ACP are as follows:

- Managing the competing demands of a busy general practice. General practices do not consider ACP urgent or as important as meeting other primary care health targets. It is therefore not prioritised or marketed.
- The time it takes to have conversations and complete a plan. General practices report that completing a plan can take between 90-120 minutes.

Canterbury DHB is funding general practices to complete plans. This recognises the time it takes to complete a plan. This funding is contributing to general practices’ uptake of ACP. However, the evaluation did not assess whether this uptake affects other consumers’ access to primary care.

Practice nurses are developing plans with consumers in many general practices that are implementing ACP well. Practice nurses often have relationships with consumers who have chronic and/or long-term conditions. Practice nurses are able to have longer conversations and can visit consumers in their homes, unlike many General Practitioners.

Although primary care is well placed to deliver ACP, Māori, Pacific, low-income, rural and disabled consumers experience barriers to accessing primary care. ACP is therefore working better in general practices located in higher income areas.

Coordinators are key in early implementation

Most DHBs have an ACP Coordinator to support ACP implementation. Coordinators are either full time or part of an existing role. Coordinators are important for ACP for the next five years as the programme matures and ACP becomes business as usual.

The New Zealand Health Survey consistently finds that Māori and Pacific peoples have poorer health and more unmet need for primary health care (Ministry of Health, 2016a).
Coordinators are valuable because they:

- increase awareness of ACP amongst health providers and administration staff
- write plans and mentor staff to write plans
- develop systems and processes for DHBs
- provide quality reviews of completed plans
- upload plans into shared electronic records
- meet with community groups to raise awareness of ACP.

Two regional implementation managers started in December 2016, based in the North Island and South Island. Their role is to improve collaboration across DHBs, facilitate the sharing of best practice and ensure national consistency. As these roles are new, the evaluation is not able to determine the value of this role.

The community has a role in ACP and is untapped

Whānau, paid community groups and volunteers could be empowered, enabled and mobilised to work with consumers to develop plans. The community has access to consumers and often has enduring relationships with them. Making use of community resources also aligns with consumers’ needs for developing a plan, such as developing a plan with someone they know or can build a relationship with, has time, and can come to their home.11

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10 The literature notes that ACP facilitators can be effective during implementation (Detering, Hancock, Reade, & Silvester, 2010; Mason, 2017). However, there is some evidence that skilled facilitators are not a sustainable solution (Lund, Richardson, & May, 2015).

11 Canadian research shows that the community has an important role in implementing ACP, especially for culturally diverse groups (Con, 2008). This role includes translating resources, interpreting, advocacy, and promoting ACP.
ACP training is effective

We used the Kirkpatrick's Evaluation Model to determine evaluation effectiveness.

Approximately 1,500 health providers have received in-depth ACP training

Professional education and development is a key component of the ACP Programme. Approximately 1,500 health providers have completed the Level 1A (one day) and Level 2 (two day) training. At March 2017, there were approximately 800 applicants for the January to June Level 2 training courses indicating there is strong demand for the training. In addition, 3,672 people have completed one or more modules of the Level 1 online training.

Most staff trained at levels 1, 1A and 2 are nurses, followed by allied and other professionals, and then doctors. Approximately one third of Level 1A and Level 2 participants are from primary care.

Approximately 75% of staff trained at Level 2 identify as European or New Zealand European. Less than 10% of level 2 trainees identify as Māori (5%) or Pacific Island (3%).

Auckland DHB, Counties Manukau DHB, Waitematā DHB, and Canterbury DHB have the highest uptake of levels 1, 1A and 2 training. Waikato DHB has very low uptake for training. Only six staff are trained at Level 2 although the DHB covers a population of over 359,000 (Statistics New Zealand, 2013).

Reaction to training

Health providers enjoyed training, and thought it was valuable. Some providers and employers consider the Level 2 training costly and long.

The training aligns with best practice adult learning. It is interactive, focusses on real challenges and fosters peer-to-peer interactions in a safe environment. Programme monitoring data shows that health providers think the role-plays and facilitation skills are excellent. Monitoring data also shows that over 80% of health providers thought the training was interesting, useful, informative, and met their needs.

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12 Professional education and development is a key component for implementing ACP (Blackford, Strickland, & Morris, 2014; Gilissen et al., 2017; Mason, 2017). This includes communication training at undergraduate and professional level in ACP, palliative and end of life care (Con, 2008).
13 Level 1A and Level 2 trainees are required to complete the online training before attending the day courses. However, not everyone does so. In total 4,172 people have registered on the website. Not all of those registered have completed any of the modules. Website data collection for participants completing Level 1 is not yet accurate. The ACP programme is working with the website provider to gather accurate data in the future.
14 Ethnicity data not available for Level 1 or 1A
15 The health workforce in New Zealand has low Māori and Pacific Island representation (Ministry of Health, 2016b).
Ninety five percent of participants\textsuperscript{16} said the training was relevant to their work. Participants consider the facilitators, presentations, and materials excellent. However, Level 2 participants are significantly more likely to find the training ‘very relevant’ than level 1A participants. Level 2 participants found working with actors valuable.

It is challenging for many health providers to attend the Level 2 (two-day) course. General practices in particular find it difficult to attend the two-day course. General practices need to backfill positions when they attend training which is costly. Secondary care also finds it challenging to backfill positions for staff to attend the course.

Level 2 training is costly but comparable to other two-day health professional development courses in New Zealand. Effective advanced communication training is expensive because of the resources required. The programme delivers training regionally which is more affordable than bringing staff to main centres or sending them overseas.

Learning outcomes

Training improves providers’ confidence and skills to have conversations with consumers

An analysis of post training evaluation forms found that participants felt more confident initiating and developing plans because of the training. They also felt more confident having difficult conversations with consumers. The Deloitte 2015 Evaluation reported that trainee confidence levels are maintained up to one year following training (Deloitte, 2014).

More than 90\% of participants reported that the training was effective at increasing their understanding of ACP and increasing their ability to explain what a plan is to consumers. The same high percentage reported that training was effective at improving their ability to work with consumers to develop plans.

Behaviour change

Providers report applying learnings to practice. Consumers felt trained health providers listened and were knowledgeable, empathetic and professional

Over two thirds of participants reported developing plans with patients as part of their routine care practice. Of those who developed plans, most (74\%) report that they are keeping a record of planning conversations in consumers’ notes most/all of the time. Two-thirds of participants (66\%) report asking consumers if they have plans most/all of the time. Nearly half (47\%) report developing plans with consumers most/all of the time.

However, of those who routinely develop plans with patients, only 47\% report using plans to inform patient care most/all of the time. Furthermore, only 34\% report including plans in patient referrals most/all of the time.

\textsuperscript{16} In this section participants refers to people who completed or partially completed the Litmus ACP survey (n=483).
Almost one third of participants do not routinely develop plans with consumers. The most common reason for this is lack of time and limited opportunity.

Participants who had done Level 2 training were significantly more likely than those who had done Level 1A training to consider the training effective at enhancing their understanding and skills.

Our data collection methods did not allow us to observe participants’ conversations with consumers to develop plans. However, consumers’ who had developed their plans with trained health providers felt providers listened to them, and were knowledgeable, empathetic and professional.

Results of training

Training is contributing to consumers achieving their future and end of life goals

The training enables health providers to have conversations with people to plan their future and end of life treatment and care. We cannot make a definitive call that training has resulted in consumers achieving their future and end of life goals. This is due to the complexity of ACP and the health system. Many other factors inside and outside of the programme contribute to this result. These include having accessible and shared plans, health providers acting on plans, whānau agreeing with plans, and consumer and whānau health literacy and advocacy. However, we can say that training has contributed to this goal.

ACP training is filling a gap in communications training

Two thirds of participants had not completed communications training other than ACP training in the previous three years. Of those that had done communications training this included in-house supervision and non-medical training. There is an opportunity to redesign Level 1A and/or Level 2 courses to meet the health workforce’s need for advanced communication training.

Advanced communications training is limited in New Zealand. Communications training is limited at undergraduate and postgraduate levels and in the workforce. Some undergraduate and specialist training such as general practice or palliative care include advanced communication skills. In addition, the following training is available:

- Specialists from Capital and Coast DHB and Auckland DHB provide advanced communications training through private sponsorship
- Healthy Conversation Skills Training (University of Auckland)
- Medical Protection Society communication skills workshops
- Connect Communications
- Communication Skills initiative course
- Auckland University Palliative Care training and Mercy Hospice include communications training within their courses and workshops as do other hospices around New Zealand.

This list is incomplete. A detailed review of communications training is needed to identify training needs and gaps. Advanced communication training is also available internationally.
The ACP National Forum needs refreshing

In November 2016, the cooperative held its first two-day ACP National Forum. This forum enabled health providers, NGOs and consumers to share learnings and to network. However, the two-day forum was lengthy, costly and attracted the ‘usual suspects’.

There is value in holding forums. However, future forums need to deliver more value for fewer resources. Ways to achieve this would be to define a clear purpose for the forum (for example, to share best practice or to tackle a specific issue) and to review the two-day format.
Resources could be improved

The programme has a wide range of resources developed with consumer, whānau and health providers

The programme has developed a range of ACP resources and toolkits to support consumers, whānau, and their health teams to have conversations and develop plans. The cooperative consulted with consumers, whānau, and health providers in the development of many of these resources.

Resources include brochures about ACP, templates and forms for consumers, whānau and their health teams to support conversations and complete plans. Resources also include promotional material such as posters, pamphlets, and postcards to raise awareness of ACP.

The programme has a comprehensive website on ACP, including resources, stories and news about ACP. The programme also developed a community volunteers’ toolkit to help communities think and talk about death and dying.

Resources are not user friendly

Some providers mentioned the resources were too long and not user friendly when having conversations with consumers.

An ACP coordinator or nurse mainly led consumers interviewed through the ACP process. Consumers therefore did not have to depend on resources to complete a plan.

Resources are mainly in English

The following resources have been developed in other languages and cultural models:

- He Waka Kakarauri: Guidelines for Engaging Māori in Advance Care Planning Conversations. The Northland Māori Advance Care Planning (ACP) Working Group developed this model for Northland District Health board
- Advance Care Planning – Korean.

Pacific people would prefer to have resources in their own languages. This is particularly important if the health provider who is helping them to develop their plan does not speak their language.

Resources are not visible to consumers

Consumers and whānau note a lack of visibility of ACP resources in general practices and other health and community settings that they visit regularly.
Plans need to be accessible and easy to share

The current system of storing and locating plans is resource intensive

In Canterbury DHB, all plans are loaded into the shared electronic system. To ensure quality, a small team check every plan for consistency and clinical accuracy. This is time and resource intensive.

In Counties Manukau DHB, plans are loaded into the electronic shared care system. This is accessible to health providers across the DHB. Responsibility for uploading the plan lies with the person who completed it (often general practice or hospice). This is time and resource intensive.

The extent to which plans are accessible and shared varies across and within DHBs

In Canterbury DHB, all hospital and general practice staff are able to see and update plans.

In Counties Manukau DHB, hospital and general practice staff are able to view plans. However, finding plans on the shared system is difficult and time consuming. Furthermore, the change to the new resources created confusion, as health providers are unable to match the new paper document to the existing electronic format.

Paramedics and ambulance staff are not able to view plans in most areas

Paramedics and ambulance staff are not able to view patient electronic health records in most areas and therefore may not know that a consumer has a plan. However, staff often ask for or look for documents in consumers’ homes to inform patient care.

In Canterbury DHB, the St Johns communication centre has access to HealthOne (shared care record). The DHB is also providing education to staff about accessing and using plans when on call.

17 Literature suggests written policies and procedures that are easy to access is an important component of achieving business as usual for ACP (Silvester et al., 2013).
There are strong benefits to being able to view plans as part of a patient’s electronic health records

A single electronic health record is being developed for New Zealand over the next few years. Future technology or resource changes should meet Ministry of Health requirements so plans can be lifted to a nationally accessible electronic records service.
Taking the programme to the community

Community meetings are effective at raising awareness of ACP

Community awareness and information giving is important for driving consumers to participate in ACP. Community meetings are an opportunity to engage with a purposeful and targeted group of consumers and whānau about ACP. Meetings provide an opportunity for consumers and whānau to discuss ACP and ask questions in a safe setting. Relationships often begin at this early stage.

Consumers who attended meetings felt the information they received was valuable and prompted them to talk to their ACP Coordinator, general practice or whānau.

Stakeholders consider this engagement method is an efficient use of resources. Furthermore, Stakeholders believe these targeted meetings have resulted in consumers and whānau asking their general practices about ACP.

Some DHBs have undertaken a large number of meetings in aged residential care facilities and hospices, and to the Rotary Club, Lions Club, Grey Power, and other targeted community groups. However, DHBs have engaged less with Māori and Pacific communities.

The return on investment for Conversations that Count Day is likely to be low

Consumers and health providers have low awareness of Conversations that Count Day. Conversations that Count Day started in 2013 as a way to raise awareness of ACP and encourage people to start talking about what they want for their future and end of life care.

Consumers are not aware of Conversations that Count Day or the resources. Health providers also have low awareness of the campaign. Providers who were aware of the campaign feel it is time consuming and resource intensive. They also comment that the day has not effectively worked with community groups.

18 Community awareness and public information is important for successful implementation and sustainability of ACP (Mason, 2017).
Consumer led public awareness campaigns may help to normalise talking about death and dying

Some stakeholders recommend that the programme invest in a public awareness campaign to normalise talking about death and dying and to raise awareness and demand for ACP. Raising awareness through community-led campaigns is likely to have a good return on investment.
Developing sustainable governance and leadership

The cooperative has been invaluable for driving ACP in the early years

Since 2010, the cooperative has undertaken significant work to establish and implement ACP throughout New Zealand.

Their achievements include:

- Creating and delivering the training programme
- Developing the ACP website and resources
- Creating Conversations that Count day
- Increasing awareness of ACP, particularly for health professionals
- Developing a community of practice for ACP
- Creating a sub-governing body in the form of the cooperative Round Table

The cooperative has drawn on the passion and knowledge of its members to implement the programme.

Leaders are championing ACP

There are ACP champions across the country working in the health sector. These champions have:

- raised awareness of the importance of ACP among their colleagues
- set up and participated in regional groups to implement ACP
- driven implementation in their specialisation areas.

The central regions ACP group includes representatives from six DHBs in the lower North Island. They support regional ACP implementation through local innovations and collaboration. They are also the central region conduit for ACP.

Within the South Island Alliance, ACP advocates have promoted ACP in their regions and with specialists. The alliance is working to develop a single South Island-wide electronic advance care plan.

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19 Research identifies leadership at the health sector and community level as key to ACP implementation (Johnstone & Kanitsaki, 2009; Mason, 2017).
20 A date for release has not yet been set. See the South Island Alliance webpages for more information https://www.sialliance.health.nz/CDF_ModuleNews/Display/Details/211?NewsSetId=32&PageId=22806
There are a few ACP consumer champions who are strong and vocal advocates for ACP in their communities. They have spoken at events on the value of ACP from personal experience.

The programme needs reliable funding

The programme has not had continuous reliable funding since it started. This has made it challenging to plan for more than 12 months. This lack of reliable funding has limited the programme’s ability to plan training, fund staff positions, and expand.21

Cooperative members are contributing time and resources beyond their paid roles. This approach is aligned with a cooperative approach but is not sustainable long-term.

21 Internationally, Seymour, Almack, and Kennedy (2010) identify lack of sufficient and dedicated resources as a key barrier to implementing ACP (see also Gilissen et al., 2017; Mason, 2017).
Monitoring, evaluation and research for the future

The programme needs a monitoring system

There is no unified monitoring system for ACP in New Zealand. A monitoring system will help track progress to achieving the intended outcomes of ACP. It will also help identify problems or ways to improve the implementation of ACP.

The programme also needs to agree on useful measures to monitor outcomes. The number of conversations or completed plans is not a useful measure for ACP. Counting the number of plans does not demonstrate the value of the process or patient outcomes. Counting the number and quality of conversations is time consuming and unreliable. Furthermore, conversations do not necessarily result in a plan.

Some stakeholders suggest that other measures might be more reliable. For example, admission to intensive care units, number of patients who die at home, or number of cardiopulmonary resuscitation in older people. Monitoring also needs to capture patient and consumer experience, and equity of access.

The new strategic plan should be evaluated after five years

The programme needs to be evaluated after the end of the new strategic plan. The focus of this evaluation will be to determine whether ACP has become an established, accepted and expected part of health care.

The evaluation will also assess the extent to which the programme achieves the four goals of the strategic plan. These goals are:

- normalise death and dying
- a prepared workforce and community
- sustainable ACP programme and communications training
- nationally equitable access to ACP.

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22 International research has found that ACP programmes use different monitoring systems (Biondo et al., 2016; Brinkman-Stoppelenburg, Rietjens, & Heide, 2014). Most programmes assessed number of plans, medical interventions, or place and type of care. The international research identified a gap in that most programmes do not assess whether the care received by the patient matched patient wishes as described in their ACP.
The programme needs research to build an evidence base

The sector should develop a strong evidence base to support a coordinated and continuous improvement approach to implement ACP. This is particularly important as the programme is emerging and evolving.

Stakeholders and consumers identified three areas for research:

- Does ACP training improve provider communication and shared decision-making and improve consumer outcomes?
- How do providers make decisions about end of life care and how do ACPs influence their decision-making?
- How can ACPs be more responsive to Māori and Pacific values and needs for death and dying?
Appendices
ACP training

ACP training has five levels

Level 1 is an e-learning course with a focus on considering ones’ own future health care and talking about ACP with patients. It is mandatory to complete Level 1 before undertaking Level 1A or Level 2.

Level 1A is a one-day interactive course. It explores in-depth ACP in practice and focuses on communication skills.

Level 2 is a two-day course that focuses on communication skills required to have more complex ACP conversations and to manage difficult reactions and barriers. It is mandatory to complete Level 2 before undertaking Level 3.

Level 3 includes a four-day course and independent learning. Level 3 training is for health providers who want to become facilitators of the Level 2 training. It is mandatory to complete Level 3 before undertaking Level 4.

Level 4 is a one to two year course for clinical leaders of the programme who work on the programme content and train the Level 3 facilitators.

Health providers are mainly accessing the online training

Table 1: Health providers who have completed training by level

<table>
<thead>
<tr>
<th>Level 1-3</th>
<th>Level 1A</th>
<th>Level 2</th>
<th>Level 3</th>
<th>Level 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>3,672</td>
<td>335</td>
<td>1150</td>
<td>11</td>
<td>2</td>
</tr>
</tbody>
</table>

Level 2 training started in 2012/13 and Level 1A training started in 2015/16.

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23 This is the number of people who have completed one or more online module since 2013. It excludes those who have registered on the website but have not completed an online module.
The majority of people trained at all levels are nurses

Table 2: Health providers who have completed the training by role

<table>
<thead>
<tr>
<th>Role category</th>
<th>Level 1</th>
<th>Level 1A</th>
<th>Level 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allied</td>
<td>267</td>
<td>51</td>
<td>142</td>
</tr>
<tr>
<td>Doctor</td>
<td>296</td>
<td>24</td>
<td>201</td>
</tr>
<tr>
<td>Nurse</td>
<td>1,377</td>
<td>194</td>
<td>723</td>
</tr>
<tr>
<td>Other</td>
<td>307</td>
<td>34</td>
<td>77</td>
</tr>
<tr>
<td>Data missing/incomplete</td>
<td>15</td>
<td>30</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>2,265</td>
<td>326</td>
<td>1,147</td>
</tr>
</tbody>
</table>

Most people who receive ACP Level 2 training identify as New Zealand European

Table 3: Health providers who have completed the training by ethnicity

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Level 2</th>
<th>(n=511)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Māori</td>
<td>28</td>
<td></td>
</tr>
<tr>
<td>Pacific Island</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>New Zealand European</td>
<td>326</td>
<td></td>
</tr>
<tr>
<td>European</td>
<td>62</td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Indian</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>South East Asian</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>Middle Eastern/Latin</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>American/African</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>26</td>
<td></td>
</tr>
</tbody>
</table>

24 Only includes data from August 2014 – August 2016. The programme transitioned online modules to a new website format during 2016. This data is not yet available.
25 Data not available for Level 1 or 1A
26 Data from July 2014 only.
DHBs are participating unevenly in ACP training

Table 4: Health providers who have completed the training by DHB

<table>
<thead>
<tr>
<th>DHB</th>
<th>Level 1 (n=2,265(^{27}))</th>
<th>Level 1A (n=326)</th>
<th>Level 2 (n=1,147)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Auckland</td>
<td>234</td>
<td>54</td>
<td>198</td>
</tr>
<tr>
<td>Bay of Plenty</td>
<td>59</td>
<td>1</td>
<td>51</td>
</tr>
<tr>
<td>Capital and Coast</td>
<td>189</td>
<td>12</td>
<td>47</td>
</tr>
<tr>
<td>Counties Manukau</td>
<td>236</td>
<td>43</td>
<td>154</td>
</tr>
<tr>
<td>Hawkes Bay</td>
<td>42</td>
<td>16</td>
<td>46</td>
</tr>
<tr>
<td>Hutt Valley</td>
<td>53</td>
<td>15</td>
<td>37</td>
</tr>
<tr>
<td>Lakes</td>
<td>17</td>
<td>-</td>
<td>12</td>
</tr>
<tr>
<td>Mid Central</td>
<td>171</td>
<td>16</td>
<td>31</td>
</tr>
<tr>
<td>Northland</td>
<td>98</td>
<td>31</td>
<td>66</td>
</tr>
<tr>
<td>Tairawhiti</td>
<td>4</td>
<td>-</td>
<td>10</td>
</tr>
<tr>
<td>Taranaki</td>
<td>82</td>
<td>13</td>
<td>24</td>
</tr>
<tr>
<td>Waikato</td>
<td>27</td>
<td>-</td>
<td>6</td>
</tr>
<tr>
<td>Wairarapa</td>
<td>20</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Waitemata</td>
<td>86</td>
<td>35</td>
<td>181</td>
</tr>
<tr>
<td>Whanganui</td>
<td>50</td>
<td>16</td>
<td>25</td>
</tr>
<tr>
<td>Canterbury</td>
<td>378</td>
<td>25</td>
<td>112</td>
</tr>
<tr>
<td>Nelson-Marlborough</td>
<td>83</td>
<td>-</td>
<td>45</td>
</tr>
<tr>
<td>South Canterbury</td>
<td>36</td>
<td>-</td>
<td>33</td>
</tr>
<tr>
<td>Southern</td>
<td>298</td>
<td>13</td>
<td>52</td>
</tr>
<tr>
<td>West Coast</td>
<td>18</td>
<td>16</td>
<td>11</td>
</tr>
<tr>
<td>Outside NZ/did not complete</td>
<td>50</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Incomplete data</td>
<td>34</td>
<td>15</td>
<td>-</td>
</tr>
</tbody>
</table>

\(^{27}\) DHB data not available for all the website data.
Training is relevant to participants’ practice

The majority of Level 1A and Level 2 participants (95%) consider the ACP training is relevant/very relevant to their practice.

![Bar chart showing the percentage of participants finding the training very relevant, relevant, not very relevant, and not at all relevant.]

**Participants who answered the question**

Level 2 participants are significantly more likely to find the training 'very relevant' than level 1A participants.

Training improves confidence, understanding and skills

More than 90% of participants report that the training has been very effective or effective at increasing their understanding of ACP, increasing their ability to explain what ACP is to patients. Almost 90% report that that the training was very effective or effective at improving their ability to work with patients to develop ACPs.

![Bar chart showing the percentage of participants finding the training very effective, effective, neither nor, not effective, and not effective at all for improving understanding of ACP, increasing ability to clearly explain ACP, improving ability to have difficult conversations, and improving ability to work with patients to develop their ACP.]

**Participants who answered the question (n=483)**

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28 In this section participants refers to those who participated in the Litmus ACP survey.
Level 2 participants are more likely to find the training very effective

Level 2 participants are significantly more likely to consider the training was very effective at enhancing their understanding and skills in relation to ACP.

![Bar chart showing effectiveness of training](image)

Participants who answered the question Level 2 (n=337), Level 1A (n=146)

Participants are applying training to their practice

Participants are changing their practice in some areas because of training. Most participants who routinely develop plans with patients are keeping a record of ACP conversations in patients’ notes and asking patients if they have plans always or most of the time. Half are developing ACPs with relevant patients always or most of the time.

![Bar chart showing application of training](image)

Participants who answered the question (n=325)
However, around one half of these participants either sometimes or never use ACPs to inform patient care. Furthermore, two thirds of these participants do not include plans in patient referrals.

Two thirds of participants routinely develop advance care plans with consumers. One third do not routinely develop plans with consumers. Of these 70% identified lack of time or opportunity as the main reason for not developing plans with consumers.

**ACP training has improved patients’ healthcare**

Nearly two thirds of participants (61%) believe that using ACPs in their practice has improved the health care provided to patients.

![Bar chart showing responses to the question](chart.png)

**Participants who responded to the question**
Background to ACP in New Zealand

In 2010, a group of committed and interested health providers established the cooperative to guide the design and implementation of ACP across New Zealand. The cooperative vision is that ‘all people will have access to comprehensive, structured, and effective advance care planning.’

In 2010, the cooperative consisted of a round table governance group and five task teams. The role of the ACP Round Table is to provide leadership and oversight over the strategic direction of the cooperative and task teams (Advance Care Planning National Cooperative, 2010). The task teams focussed on essential components of implementing ACP (clinical training, patient and clinical tools, public domain, regulation and ethics, research and evaluation).

Membership to the cooperative is open to anyone. Cooperative members come from across the sector including NGOs, the Ministry of Health, education providers, networks, District Health Boards, residential care providers, colleges, and consumers.
Evaluation approach

We undertook a mixed method approach to evaluate the ACP programme and training.

Qualitative interviews with key stakeholders, health providers, and consumers

We interviewed 65 people throughout New Zealand to inform the evaluation. Table 5 outlines the number of participants.

Table 5: Number of people interviewed for the evaluation

<table>
<thead>
<tr>
<th>Number of people</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Counties Manukau</td>
<td></td>
</tr>
<tr>
<td>Consumers and whānau</td>
<td>14</td>
</tr>
<tr>
<td>Health providers</td>
<td>7</td>
</tr>
<tr>
<td>Christchurch</td>
<td></td>
</tr>
<tr>
<td>Consumers and whānau</td>
<td>10</td>
</tr>
<tr>
<td>Health providers</td>
<td>6</td>
</tr>
<tr>
<td>Key stakeholders</td>
<td>28</td>
</tr>
<tr>
<td>Total</td>
<td>65</td>
</tr>
</tbody>
</table>

The Health Quality and Safety Commission, ACP programme staff, initial interview participants identified key stakeholders. Key stakeholders were from:

- ACP programme, including managers, trainers and implementation managers
- Health Quality and Safety Commission representatives
- DHB representatives including managers, clinical staff, and ACP coordinators
- Experts in advanced communications training for health professionals
- Community volunteers.

We also spoke with the ACP advisory group and the Central Regions ACP group.

All consumers and whānau had a plan or supported a whānau member with a plan. A key stakeholder in each DHB identified consumers and whānau.
An online survey of people who received ACP training

We conducted an online survey of everyone who has completed level 1A or Level 2 ACP training. The survey excluded Level 1, and Levels 3 and 4 trainers.

In total 1,473 surveys were emailed to participants. In total 483 people completed or partially completed the survey (33% response rate). Table 6 below outlines the survey responses.

Table 6: Survey participation

<table>
<thead>
<tr>
<th>Number of people</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total emails</td>
</tr>
<tr>
<td>Bounced emails</td>
</tr>
<tr>
<td>Unopened</td>
</tr>
<tr>
<td>Opened</td>
</tr>
<tr>
<td>Opted out (not eligible or did not want to participate)</td>
</tr>
<tr>
<td>Completed</td>
</tr>
<tr>
<td>Partial completion</td>
</tr>
</tbody>
</table>

The training was assessed using the Kirkpatrick Evaluation Model. The survey assessed trainees’ learning and behaviour.

ACP training monitoring data

We analysed ACP training monitoring data from Level 1, 1A and 2. There was no available data for Levels 3 and 4 as fewer than 20 people have received training at this level.

Training monitoring data included demographic information, and reaction to the training from post training feedback sheets.
References


Mā te rongo, ka mōhio; Mā te mōhio, ka mārama; Mā te mārama, ka mātau; Mā te mātau, ka ora

Through resonance comes cognisance; through cognisance comes understanding; through understanding comes knowledge; through knowledge comes life and well-being.

Sally Duckworth
Partner
04 473 3883
sally@litmus.co.nz

Liz Smith
Partner
04 473 3885
liz@litmus.co.nz

www.litmus.co.nz